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STRATEGIES FOR THE ECONOMIC EVALUATION OF END OF LIFE CARE: MAKING A CASE FOR THE CAPABILITY APPROACH

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SUMMARY

Economic evaluation of end of life care is increasingly expected from both research funders and those making decisions about the use of health and social care resources. There are, however, difficulties in applying the currently established evaluative methods to end of life. These are partly associated with the sensitivity of the topic and the feasibility of data collection but also, more fundamentally, a lack of agreement about the terms in which such care should be evaluated. This paper examines different theoretical perspectives from which economic evaluation of end of life care could be conducted, and argues for the application of a capability approach focusing on the opportunity for a good death. It then examines challenges with taking forward such an approach, including defining, measuring and valuing appropriate outcomes. It concludes that such an approach is viable, and explores how it might be taken forward to assist with resource allocation decisions.

Keywords: Economic evaluation; End of Life care; Capability approach; ICECAP-SCM; Close persons; Valuation; Decision making.

INTRODUCTION: CURRENT PROBLEMS WITH THE ECONOMIC EVALUATION OF END OF LIFE CARE

The evaluation of care strategies at the end of life is becoming increasingly important as, globally, the population of older people rises. Increases in healthy life expectancy have not kept pace with improvements in total life expectancy and so the number of people in need of greater care at the end of life continues to rise. Although policies to improve the quality of end of life care are being put in place in a number of countries [1-5], these inevitably have economic implications. Some policies might involve potentially high costs for governments, health services and charities, as well as limits to unpaid care provision from families or through wider social networks, whilst others may be less costly, for example where highly technological expensive interventions are used more appropriately. Indeed, recent work in the UK suggests high differences in costs associated with different models of end of life care [6]. The benefits associated with different policy options may also differ significantly and are equally important in thinking about resource allocation. The evidence base for informing such resource allocation decisions is very small, however, with relatively few economic evaluations having been attempted; a recent systematic review of evidence on the cost and cost-effectiveness of palliative care, for example, found that just one out of 46 studies meeting the review inclusion criteria was a full cost-effectiveness study [7].

Nonetheless there is a clear desire for such evaluation to be conducted [1] and economists have started to discuss the issues involved, with a number of papers appearing in recent years about the difficulties associated with conducting economic evaluation at the end of life

[8-16]. These discussions focus on the methodological and ethical difficulties associated with the practicalities of conducting evaluations at a sensitive time within people's lives. There is little agreement, however, on either the nature of the problems facing economic evaluation in end of life care, or methods for dealing with them. A recent attempt to produce guidance for economic assessments of end of life care reflects this lack of consensus [17]. This guidance contained just three, relatively non-informative, items related to cost-effectiveness within the checklist ('integrate into preliminary evaluations and test feasibility of methods'; 'Collect data on use of services... to take societal approach to care costs'; and 'justify appropriate outcome measures to generate cost-effectiveness') and a section indicating 'strongly opposing' views about the appropriateness of using QALYs [17].

It is clear that this lack of consensus on methods arises, at least in part, from more fundamental disagreements about the appropriate philosophical framework for conducting economic evaluation of interventions at the end of life [15] or, to put it another way, the different normative positions taken by economists working in this area. Whilst the main focus of all normative economics is on what 'should' be done to achieve particular ends, what these 'particular ends' are is frequently unacknowledged and, in discussions of the evaluation of end of life care, seems to have become conflated with methodological issues. Not only does this cause confusion, but it also diverts from the very real, practical and methodological difficulties, some of which may be dealt with in a similar manner, even for those working in different paradigms. Whilst any number of broad philosophical positions could be taken, three will be discussed here on the grounds that they are either currently extensively used in evaluation or are being actively developed both generally and in the context of end of life care.

The first, traditional, approach to welfare economics is welfarism. Here, the aim of economic evaluation is to determine how to maximise utility within society [18-21] so as to provide information about efficiency (distributional issues are then left to the political system [20]). Utility is concerned with fulfilling desires [20] and can be seen as 'a numerical representation of preferences' (Hargreaves Heap [22], p.368). Whilst it is assumed that individual utilities are not comparable, the notion of hypothetical compensation is utilised to ensure that decisions that have both losers and gainers can be evaluated [23]. The approach is generally, although not exclusively, operationalised through cost benefit analysis [24] in which utility benefits are estimated through individuals' preferences in terms of willingness to pay. The focus then becomes the values or preferences that individuals themselves bring to the decision and, in relation to end of life care, implies a focus on the preferences of those at the end of life as well as on the preferences of others affected by decisions. One issue that may be particularly pertinent to welfarists concerns recent evidence that those at the end of life place a higher value on this period of time [25, 26]. This may be because the value of resources once dead is zero [27] and/or because people at this time wish to retain hope [27] and avoid 'regret' from not trying all possible options [28, 29]. This concern about the value of time to individuals at the end of life is then reflected by some economists working in economic evaluation of end of life, who view the summation of time gained from an intervention (adjusting for the value of quality of life experienced during that time) as problematic for the evaluation of palliative care interventions [9].

A second approach, and the one most commonly seen in current practice of economic evaluation across healthcare is the health maximisation approach, associated with one version of extra-welfarism [18, 19]. Here the emphasis is on maximising health, rather than utility [20], with health usually expressed through a particular interpretation of the Quality-Adjusted Life-Year as a measure of health status valued by the general population [20]. In

this paradigm, end of life care is seen as just another form of health care that should be, largely, evaluated in the same way as all other conditions, with a maintained focus on whether end of life care produces gains in health [16]. An issue that currently exercises extra-welfarists of this persuasion, particularly in the UK, is the decision by the National Institute of Health and Care Excellence to apply a different threshold to (some of) those with end of life conditions. This is perceived as unjustified [16] and is producing a growing literature exploring societal values on this issue [30-32].

A third approach would be to take a broader extra-welfarist perspective. In such an approach, the basic criteria of the extra-welfarist approach (going beyond utility in assessing outcome, not being restricted to individual preferences, allowing weighting of outcomes and explicitly allowing interpersonal comparison of outcomes [18]) would be met, but the broader approach might also relate to other philosophical criteria such as those associated with the capability approach advocated by Amartya Sen [33]. Such an approach is clearly less developed than other approaches, but may offer a promising way forward.

This paper takes the position that it should be incumbent on all those conducting economic evaluation, but particularly those discussing methodology, to be clear about the underlying theoretical basis for their work. Where methodological choices then derive directly from the underlying theoretical basis, critiques of the work should focus on that underlying theoretical basis and not on criticising the proposed methods as if they derive from a different basis. (Of course, this should not preclude criticism of methodology that is poor in respect of its own theoretical base.) For example, Round's discussion of end of life care clearly derives from the theoretical basis of health maximisation [16], yet the paper makes numerous criticisms of the issues discussed, and approaches advocated, by both Coast and Lavender [34] and Normand [8], without acknowledging the different perspectives from

which these authors start their analysis. Consequently, issues that are important from some perspectives are dismissed as irrelevant [16].

Taking this position, the paper begins by setting out the broad principles from which it derives its philosophical basis. It then provides an outline for a suggested approach for evaluation of end of life care based on the capability approach, before detailing some of the challenges in taking the methods forward as well as considering the potential for dealing with these methodological challenges.

CHOICE OF UNDERLYING PERSPECTIVE: AN EXTRA-WELFARIST CAPABILITY APPROACH

As indicated, there are three broad normative theoretical bases that economists are likely to choose from: welfarism; narrow extra-welfarism interpreted as health maximisation; or an alternative extra-welfarist perspective focusing on opportunity for a good death.

Fundamentally, these differ according to their evaluative space – what it is that we are interested in evaluating – and indeed, by that definition of the evaluative space, who is included within that.

A welfarist approach focusing on the utility (happiness or preferences) achieved by patients themselves at the end of life might seem entirely appropriate. After all, it is patients and those close to them who directly experience the death, and therefore their preferences or values should be what ‘counts’ in decision making. It is worth noting that in the welfarist cost benefit approach, costs and benefits to all are included, so these impacts on family and friends would be included within the analysis. It also fits with policies to meet individuals’ preferences, for example, in relation to location of death [35]. There are two arguments that can be made against this philosophical position. The first is that focusing just on utility may be too narrow and may miss other important aspects of care that cannot be measured in terms of utility or happiness [33]. Second, this approach seems inherently subject to, potentially significant, adaptation effects [36] as patients become gradually and progressively more limited by their condition or, more worryingly, in some cases accustomed to poor levels of care.

The standard extra-welfarist approach to end of life care would apply cost-effectiveness analysis to end of life care with interventions being chosen on the basis of maximising the Quality-Adjusted Life-Years (QALYs) gained, where QALYs are a value-based measure of health status. Applying standard health economics notions of maximising the total health benefit from interventions designed to provide supportive care at the end of life seems inappropriate given that, the objective of care at the end of life is not focused purely on health improvement [37-41]. Assessment of a good death seems unlikely to be fully captured for the dying person in terms of improvements in morbidity and/or mortality; it seems even less relevant to the loved ones of the dying person. There is some discussion as to whether those beyond the patient should be included within this approach; although the usual approach is to include only the patient, there are recent examples of decisions where the impact on family has been included [42]. For some working within this approach there is a clear imperative to include only the patient on the grounds that otherwise this may divert resources from patients without people who are close to them [16]; this can of course be seen as positive or negative. There is also no element of the evaluation of choice in such an approach, where a service which enables individuals to opt for a dignified death without life-lengthening interventions would be evaluated as less beneficial (i.e. providing less in terms of gain in health) than one in which persons are automatically provided with life-lengthening interventions, even where these are not wanted.

An increasingly important approach to evaluation, particularly prevalent in the human development literature, is the capability approach [43], drawing on extensive work by Amartya Sen [33, 44, 45] and others [43, 46-50]. Sen focuses on the importance of evaluating interventions according to their impact on individuals' 'capability wellbeing', that is, what a person is able to do or be in their lives. Sen uses the example of a person who is starving due to lack of food compared with a person for whom food is freely available but who chooses to

fast, to illustrate why capability (ability to eat in this case), rather than functioning (having eaten), should be the important focus of evaluation [33]. A more relevant example in the case of end of life care might be two individuals, one living in an area where there is hospice provision and one where there is not. The individual in the first area may not choose to use the hospice care available, preferring to receive care from family members; the second, who may not have family and would have used hospice care if it had been available would look the same as the first individual in terms of functioning (i.e. no hospice care received), but in terms of capability (ability to access hospice care) is clearly worse off. An appropriate focus for the evaluation of end of life care might therefore be to consider different care strategies in terms of the capabilities that allow a person, and their family and friends, to have a good experience of end of life. Such an approach would fit within the broader extra-welfarism described by Brouwer and colleagues [18]. This approach would focus on the important capabilities arising from supportive care provision but, because of the focus on capability rather than functioning, would allow for choice and the ability of people to decide themselves how to manage the end of their life. The approach also suggests the inclusion of impacts on family and friends within the analysis given that their capability might also be affected.

In line with many others from across a number of disciplines, this paper sees the capability approach as offering a valuable starting point for thinking about the analysis of end of life care, because of its different evaluative space. This paper is therefore situated broadly within the extra-welfarist, capability approach and starts from the theoretical perspective that the appropriate focus for evaluation of end of life care is the opportunity for a good end of life experience. Such a good end of life experience may require us to evaluate capability wellbeing for the person who is dying concurrently in terms of both quality of life and quality of death: in practice, the boundaries between living and dying are blurred, with

curative and palliative interventions often delivered concurrently [9, 51-53]. It may also require us to take account of family and loved ones [11, 12] who may experience significant social and economic burden [54] and at whom some caring interventions may be (jointly) targeted [55, 56], or who may experience a distressing bereavement if the death is sudden and there is no opportunity to say goodbye or make preparations. It will also require us to consider how to value these different aspects of a good end of life experience, and how to use these in decision making. Each of these is likely to be challenging, and the paper now considers these challenges.

CHALLENGES FOR IMPROVING ECONOMIC EVALUATION OF END OF LIFE CARE WITHIN THIS BROAD APPROACH

Challenge 1: Determining what capabilities are important to individuals at the end of life

There is dissension among advocates of the capability approach about the extent to which different capabilities should be considered in different evaluations. Nussbaum recommends developing a single set of capabilities that are important in all situations [46], whilst Sen and his supporters indicate that they do not endorse the approach of a single list [49, 57, 58], with Alkire suggesting that “no one set will do for every evaluation” (Alkire, p.119 [47]). This paper takes the latter view, that the evaluation of different sets of capabilities may be important in different broad contexts. Although the capability approach is starting to make inroads into the economic evaluation of health care interventions, just one of a number of challenges for end of life care is that, although tools are starting to become available (indices such as ICECAP-O [59-61], ICECAP-A [62-64], Oxcap-MH[65]) for measuring and valuing capability, they concentrate on capability wellbeing in relation to a ‘good life’ rather than a ‘good death’.

A focus entirely on health alone has already been rejected; although there may be important health-related capabilities around reducing physical discomfort, there may be other important capabilities arising from end of life care that cannot be measured in terms of

health. Those faced with imminent death may define wellbeing differently from healthy individuals, and health status itself may assume less relevance than, for example, spiritual dimensions or preparation for death. Factors such as the ability to prepare for death [38, 39, 66], to receive spiritual comfort [38], to be treated with dignity and respect [41], to influence the care received [37-39, 41] to receive love and support [37, 40] without feeling oneself to be a burden on others [37, 41] and to achieve a sense of completion in life [38, 39] may become important in assessing capability wellbeing at the end of life, in addition to issues such as pain and symptom management [37-39, 41]. Until recently, the measures available for use with patients at the end-of-life [67] have not been helpful for use in a capability approach to resource allocation/economic evaluation as they are too long to easily attach values to, and/or are insufficiently generic (for example focusing on cancer patients alone).

Recent research, however, has aimed to find out what capabilities are important to people in terms of end of life care [68, 69]. In-depth interviews were conducted with twenty-three older people: older people in the general population; those living in residential care; and those receiving palliative care. There are clearly concerns about potential adaptation to poorer situations by those approaching the end of life, particularly where the care provided is poor. Equally, however, people's feelings about what is important to them at the end of life may change in unforeseen ways with that experience. It was therefore seen to be important in finding out about important attributes of end of life care to include those at various points along the trajectory towards death. Interviews covered what informants believe to be important about end of life care, dying and death [14, 68, 69]. Interviews were analysed using constant comparative methods to develop conceptual attributes of importance for a measure of a good death; repeat interviews were conducted with twelve informants to check conceptual attributes and develop wording for the measure. From these interviews, a descriptive measure, referred to as the ICECAP Supportive Care Measure, or ICECAP-SCM

has been developed [69]. The measure has seven attributes based on what people felt was important to them: autonomy, love, freedom from physical suffering, freedom from emotional suffering, dignity, support and preparation. Each attribute is expressed in terms of capabilities and described by one of four levels ranging from full capability, through some capability and a little capability, to no capability, with these levels expressed in terms of time rather than severity. Examples of the types of descriptive statements are: *'I can make decisions that I need to make about my life and care some of the time'*; *'If I want to, I can be with people who care about me most of the time'*; *'I am able to have the help and support that I need only a little of the time'*; *'I have not had the opportunity to make any of the preparations I want to make'* [69]. This measure may provide an appropriate way forward for meeting the challenge of measuring the benefits of end of life care in terms of capability associated with a good death, but clearly, as with all measures, information is required about the validity, reliability, sensitivity to change and acceptability of the ICECAP-SCM. This is particularly the case given that one limitation of the measure is that it was generated with older people.

The question of whether life itself (one of the fundamental capabilities within Nussbaum's taxonomy [46]) is an important element of a good death is a further challenging issue. For the ICECAP-O [59, 60] and ICECAP-A [62, 64] measures (generic measures of capability wellbeing), life can be captured in that a person who has died has no capability and their loss of wellbeing through loss of life can be assessed accordingly. It is also possible to estimate gains in years of full capability equivalence by adjusting the ICECAP instruments for time [64]. For a good death, however, death itself may not imply a loss of capability, but the timing and nature of dying may instead be an integral element of the dying person's capability. This suggests a fundamental rethink is required in how to account for time within the approach, which may be akin to valuing pathways of care as suggested by

Normand [9] (albeit that his work is more focused on utility maximisation) or may require time spent in the end of life period to be considered directly as an element of a good death.

The issue of capturing benefits to family, friends and loved ones – hereafter referred to as ‘close persons’ – is equally, if not more, challenging. There are similar issues in relation to methods for capturing capabilities for close persons in relation to end of life care, although the capabilities themselves are likely to differ. There are also, however, questions about precisely whose capabilities should be captured, suggesting the importance of understanding the social networks around those who are at the end of life [70].

Participatory empirical work could be used to explore the important aspects of capability wellbeing for close persons. Again, it will be important in such work to capture perspectives from close persons where patients are at different points in the dying trajectory and during the bereavement period, where patients have different trajectories towards death (including trajectories associated with sudden death, terminal illness, organ failure and following frailty and decline including dementia) [71, 72], in contexts with differing end of life provision [1] and where there are differing family dynamics. This will enable the influence of any adaptation to poorer states to be captured, as well as providing sufficient variation of experience to be sure that all important aspects of capability wellbeing are captured. The extent to which a close person’s capability is enhanced through doing their best to provide a good death for their loved one, despite losses in their own personal wellbeing (known as ‘agency’ [33] within the capability literature) may also be important to ascertain.

Challenge 2: Measuring capabilities at the end of life

It is one thing to determine what capabilities are important at the end of life, and another to determine how they should be measured. There are a number of important issues both in terms of the extent to which the different options are consistent with the capability approach and in terms of their feasibility in an ethically sensitive area. This section focuses primarily on measurement of capability in relation to end of life care for the dying individual, rather than for the individual's loved ones, but, again, many of the issues are similar across the two areas of focus.

A particularly difficult issue in assessing capability wellbeing for people at the end of life is who should do this measurement. One option would be that individuals themselves could indicate their own level of capability wellbeing, for example using an instrument such as the ICECAP-SCM [69]. An advantage of this sort of self-assessment is that individuals themselves hold the greatest level of information about their own capabilities, particularly perhaps when they have a capability that they choose not to pursue in terms of function. A disadvantage is that individuals who have, for example, received poor care, particularly if over a long period, may have adapted to this poor state. Their measures may be affected as a result. Evidence of such adaptation might be obtained if those on a long downward trajectory towards death are compared with those on a much shorter trajectory. If the former have a tendency to rate what appear to be similar or worse situations more highly than the latter, this might provide evidence of adaptation. Similarly, if those in receipt of much poorer care were to rate their care in a similar way to those receiving much better care, this might also provide evidence of adaptation. The difficulty with such analyses, of course, is having some clear objective measure of poor and good care that can be used to make such assessments.

If measures are to be completed by others, who should these others be, and would their assessment necessarily be more 'objective'? A family member may have witnessed a 'good' death for their loved one but if they have also experienced significant caring burden themselves, their assessment of the death of the patient may be affected by their own perspective; distress about the illness and death itself may also influence their perceptions about the dying person's capabilities. Similarly, health care professionals' assessments may be affected by factors such as whether the patient is compliant. Among both family members and health care professionals, there may be a lack of awareness about whether the patient really did or did not experience particular capability wellbeing levels. This may be of particular importance in relation to aspects such as emotional suffering, where patients may have gone to great lengths to hide their feelings, especially from loved ones.

There are also issues about the feasibility of completion by different groups. Those at the end of life may suffer from fatigue and pain, making them reluctant to complete measures; at times they may be physically unable to do so. Clearly it is also impossible for dying individuals to evaluate their care in retrospect. It may be difficult to ask families about the death of their loved one until a particular interval has passed following bereavement; by this time, families themselves may have adapted to, or rationalised, any issues around the death of their loved one. Health care professionals are often very busy; and different health professionals may have experience of different aspects of care for an individual, without any one professional having a full picture. For example, if a patient's pain is well controlled during the day but not at night, the nurses on duty at these different times may have very different views of a patient's capability wellbeing, in terms of their freedom from physical suffering. Further, some individuals may not be receiving (extensive) care from health professionals, and there may therefore be no such person who can provide such information.

Such issues clearly need further exploration. It may be that the most objective assessment of whether a person has had high or low levels of capability wellbeing at the end of life is through a combination of these different assessments, but this generates further issues around the combining of different views, and requires an explicit understanding that measures completed by different individuals are unlikely to be interchangeable. The validity and reliability of any such attempts to combine across sources of measurement also need exploration.

Challenge 3: Valuing capabilities at the end of life

There is then the important methodological question of how to weight end of life capabilities, as for example captured in instruments such as the ICECAP-SCM, so that they are helpful for use in resource allocation decision making. In principle, the methods for valuation should be ‘done with critical examination, with self-scrutiny, and where relevant, involve the discipline of public reasoning’ (Sen, p.94 [73]), but in practice it remains unclear as to how such valuations should be achieved [49].

Given the critique of individual mental states of preferences as an indicator of capability wellbeing, it would be problematic for the capability approach to then rely on personal preferences regarding capabilities. This suggests that weighting or valuation should not, therefore, be undertaken by individuals themselves given the concerns within the capability approach about the distorting impact of adaptation. Drawing on Cookson’s arguments [74], general population values might be assessed instead, as utilised for the generic ICECAP measures [60, 64]. Such general population values may be used to provide at least a starting point for generating a standard set of values for use in decision making [74], reducing the

potential for including adaptive effects. On the other hand, end of life care is perhaps unique in that (unlike, for example, poverty, or poor health) each individual experiences the end of their life on only one occasion. There may be genuine changes in what is important to a person at this point in their lives that are not just related to adaptation to a poor situation, but that represent a true difference in what is valued when death is imminent and when an individual has only a short time remaining. The general population then may have only a limited grasp of such altered values. This suggests that there does in fact need to be some attempt to find out about the values of those at the end of life.

As well as theoretical issues about the appropriateness of using values obtained from different groups, there are also issues of feasibility to contend with. Amongst the general population, for example, there may be difficulties in valuing aspects of capability wellbeing by those who may have little or no experience of important attributes of capability wellbeing at the end of life (for example, being able to prepare for death) in the context of their own death or those of loved ones. Values may thus be very hypothetical even where there are very good descriptions of attributes within the valuation exercise. For those at the end of life, the feasibility issues are likely to be considerably greater. Those at the end of life may not wish to be burdened with providing capability wellbeing values, and perhaps even more importantly, the professional gatekeepers acting as advocates for their patients may be unwilling to facilitate access to them for such purposes. Where access is obtained, researchers may need to be particularly aware of the importance of minimising burden by having both cognitively undemanding tasks, and short tasks that will not excessively tire individuals. One such method may be best-worst scaling [75] which has been used previously in the valuation of ICECAP-O and ICECAP-A and which seems to be less cognitively demanding than other techniques for understanding values. The method generates an interval scale and information about the relative value of changes in wellbeing

is measured between 1 (full capability) and 0 (no capability) [60]. Even this relatively brief and simple task, however, may be perceived as excessively burdensome by individuals, by health professionals acting as ‘gatekeepers’, and by ethics committees. A further alternative that remains largely unexplored would be to obtain values from health and care professionals as individuals who through their experience understand the important capabilities for those at the end of life.

The potential for deliberative roles within the valuation of capability indices remains an important area for future research. Given that there may be more difficulty in utilising Cookson’s arguments [74] for capability at the end of life, it may be that there are stronger incentives in this area to test a more deliberative approach.

Challenge 4: Using end of life capabilities in decision making

All current health economics approaches have retained a maximisation principle as the basis for decision making. An important aspect of the capability approach however is that it does not accept that policy making should be based on a single principle: “... no one principle – for example, efficiency maximisation – suffices for normative economic problems. Rather, a plurality, not only of informational ingredients, but also of combining principles, should be considered” (Alkire, p.124 [47]). In relation to end-of-life care in particular, the notion of maximising total capability no matter to whom it accrues may make less sense than other possible decision rules. Other rules, for example, might include the notion of maximising the number of people who experience a (sufficiently) good death, or improving the lot of those who currently have the worst experiences.

A concern with distributive justice may, indeed, suggest that in allocating resources, it is particularly important to increase the proportion of individuals reaching a minimum threshold of capability wellbeing [76]. Indeed, 'Nussbaum passionately advocates that people all over the world should be entitled, as a matter of justice, to threshold levels of all the capabilities on her list...' (Robeyns, p.115 [77]). One option for evaluating the distributional element of the provision of a 'good death' would, therefore, be to utilise and adapt the sorts of multi-dimensional poverty measures developed by Alkire and Foster [78] (where poverty here relates to poverty in terms of capability wellbeing) which use this notion of a threshold value beyond which an individual can be considered to be in poverty. One could argue, for example, that for a minimally acceptable death all people should have at least a little capability for each of the seven attributes within the ICECAP-SCM, and that policies that move people from having no capability to a little capability should be prioritised over those that move individuals from a little capability to points higher up the scale.

Participatory approaches could be used to explore the issue of what combining rules are advocated by the population generally and whether the maximisation of total benefit no matter to whom it accrues (as in a standard QALY-type analysis) is seen as acceptable in the context of end of life. Such participatory approaches are likely to be most successful where there are opportunities to reflect and respond to the views of others, to debate issues and understand points of difference. The use of focus groups is likely to be particularly advantageous in such participatory approaches. For such approaches to be successful, however, it is important that discussions are not too abstract, and that those involved can see the implications of different combining rules for the actual allocation of resources.

This discussion has focused on decision making in the abstract, but of course, it will need to be tied into the structures for end of life care provision in different countries, systems and

settings. Even in countries with single provider health systems, such as the UK, end of life care is provided through a variety of providers, including the health and social care systems and a large number of charitable funders. This makes the decision setting somewhat different to the setting for publicly funded health care, and may mean that both different priorities and different decision rules may be appropriate. Particularly problematic is that some decision makers, for example in the health sector, may have to weigh the benefits of investing in end of life care against other calls on their budgets, whilst others, for example in the charitable funding sector, may be more concerned about decisions between alternative forms of care provision.

EXPERT COMMENTARY

The paper began by focusing on the important question of what actually is to be achieved through the use of economic evaluation, and argued for the use of a capability approach in evaluating end of life care. It then focused on the many research challenges that arise. The paper sought to categorise and describe these challenges, which range from questions about what precisely should be measured and valued, to questions about how such information should be utilised in decision making. It is clear that those addressing the problem of economic evaluation from a welfarist or a narrowly health-focused extra-welfarist perspective will each face some of the issues discussed here, but not all of them. For example, researchers working within all three perspectives may have concerns about the feasibility of obtaining information from those at the end of life. Some issues, however, are particularly pertinent within the capability approach, for example, the concern with trying to avoid adaptation impacting on assessment, but are not (as) relevant to other perspectives.

Of course, there are other challenges that have not been considered here in such depth. One is the question of how to determine whether a person is at the end of life. This is clearly of fundamental importance if a different form of evaluation is proposed for those at this stage of life. End of life could be defined in terms of the health care process – by diagnosis or prognosis – or by the person themselves through, for example, decisions to discontinue curative treatment. For many patients, however, there may not be a clear terminal diagnosis, and although dying patients may be defined retrospectively (and for sudden death this may be unavoidable), for prospectively evaluating capability wellbeing, this is unhelpful. One option is the expectation by professionals of a particular life-expectancy (using an assessment of whether a clinician would be ‘surprised’ if a person were to die within the next 12 months)

[79]; this method is sometimes used for putting in place end of life services and so seems to offer some potential, but evidence for its use is poor.

Both the provision of end of life care, and the economic assessment of policies and interventions at the end of life are becoming acknowledged areas of policy relevance and there is a growing understanding that the tools for economic assessment are currently lacking and that the whole area is under-researched. The capability approach potentially offers a more comprehensive approach to economic evaluation of end of life care and tools for use within the approach are starting to be developed [69]. It is not yet clear what the support for the use of the capability approach in this context will be, but it is worth noting that in the evaluation of social care more generally in the UK, there has been institutional support from both the Social Care Institute for Excellence [80] and the National Institute for Health and Care Excellence [81] for the use of measures developed within a capability approach. This offers some hope that a broader perspective than that of health alone might be considered equally important for the evaluation of end of life care; the level of support will, of course, influence both the funding and the practical support that will enable progress.

FIVE YEAR VIEW

Despite some recent signs of improvement, many countries are still facing pressures on budgets for areas such as health and social care; these are anticipated to remain for the foreseeable future. The requirement to show value for money in such spending is thus only likely to increase. In relation to end of life care an increasing insistence on rigorous evaluation both of the effectiveness and cost-effectiveness of interventions and care can be expected, and to achieve this, it is vital that the economic tools available are fit for purpose.

Some countries, where the focus is already broader than that found in the cost/QALY approach, may already have sympathy with the approach outlined here. Even in countries such as the UK, where the cost/QALY approach has been dominant in recent years, there is starting to be an acknowledgement that health maximisation as an objective even within health care interventions may be insufficient. In the UK this is expressed through the discussions around value based pricing which have considered a greater focus, for example, on carers and productivity [82]. A broader perspective on economic evaluation of end of life care may become increasingly acceptable over the next five years. The recent provision of EU funding specifically to tackle some of these research issues in relation to a capability approach to resource allocation at the end of life through the EconEndLife project, already suggests some support for the approach amongst research funders.

In the coming years, it is likely that there will be both methodological development within the economic evaluation of care at the end of life, and also more conduct of such evaluations. This will offer the opportunity to further develop methods within the context of ongoing evaluations – essentially, trying things out in practice, and finding out what does, and does

not, work. It also offers the opportunity to work closely with palliative care researchers to generate common approaches to evaluation. The EconEndLife project expects to report on a number of areas discussed in this paper in the coming years including: feasibility of asking end of life patients, close persons and health professionals to complete capability measures; values for the ICECAP-SCM; important attributes to capture in a measure for close persons; extent of the social network that should be captured by measures for close persons; and the use of such capability measures in decision making. Other research that might be important from this perspective includes explicitly examining whether measures are appropriate and valid across different age groups and those with different conditions.

In practice, taking forward the challenges outlined here requires both creativity and funding, but the rewards are potentially high, and even some advances over the next five years could radically change how we approach economic evaluation of interventions at the end of life by the end of this period.

KEY ISSUES

- Economic evaluation can be conducted from three main philosophical perspectives: welfarism; narrow extra-welfarism using the cost/QALY approach; a broader extra-welfarism often associated with Amartya Sen's capability approach.
- There are many methodological challenges associated with the evaluation of end of life care, associated with defining, measuring and valuing appropriate outcomes.
- The perception of the methodological challenges differs according to the philosophical perspective and the paper argues that such perspectives should be made clear in critiques of methodology.
- The paper argues for a philosophical perspective based on the capability approach, with the opportunity for a good death for both the dying person and the persons close to them as an appropriate outcome.
- The ICECAP Supportive Care Measure is the first outcome measure to define the outcome for the dying person in line with this philosophical approach and offers a way forward, but evidence about its validity is still required; work is also required on the important outcomes for the dying person's family and friends.
- One challenge in measuring capability at the end of life is to determine who should complete measures and better understanding the benefits and disbenefits of completion by different stakeholders

- Another challenge is to establish how to value capability measures, whose values are appropriate and how feasible and meaningful such values are.
- A final challenge is to incorporate such measures in decision making.

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REFERENCE ANNOTATIONS

**** Highlights**

(9) Normand C. Setting priorities in and for end-of-life care: challenges to the application of economic evaluation. *Health Economics, Policy and Law* 2012;7(4):431-9.

An excellent discussion of the challenges involved in applying economic evaluation from a welfarist perspective, with a focus on issues such as accounting for the value of time in such evaluations

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An important paper clarifying the nature of the extra-welfarist approach within health economics and setting it within the context of welfarism.

(29) Sen A. Capability and well-being. In: Nussbaum MC, ed. *The quality of life*. Oxford: Clarendon Press; 1993.

A clear exposition of the capability approach from Amartya Sen.

(58) Sutton E, Coast J. Development of a supportive care measure for economic evaluation of end-of-life care, using qualitative methods. Palliative Medicine 2014;28:151-7.

A paper outlining the development of a descriptive system for use in evaluating capability at the end of life.

*** Highlights**

(16) Round J. Is a QALY still a QALY at the end of life? Journal of Health Economics 2012;31:521-7.

An analysis of methods for evaluating end of life care from the narrow health-maximisation extra-welfarist perspective

(39) Robeyns I. The capability approach: a theoretical survey. Journal of Human Development 2005;6:93-114.

A very helpful overview of the capability approach.